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Title: Are you delivering trans positive elder care?

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Keywords

Trans, cultural competence, cisgender, cisnormative, trans aging, trans positive, social care.

Abstract

For the vast majority of cisgendered people who experience alignment between the sex they were assigned at birth, the body they have and the gender identity they are comfortable with (Schilt and Westbrook, 2009), the experience of trans people is a distant one. More of us share an experience of aging and the associated concerns about reduced independence, deterioration of health and increased need for care and support.

For trans elders, the experience of ageing has specific features that have a major impact on their lives if not understood, planned for and responded to appropriately. This paper presents findings from a qualitative study exploring trans people's experiences, concerns and suggestions for how agencies providing elder care can better meet their expectations (Jones, 2013).

The research revealed low confidence in the ability of current aged care services to meet the needs of trans elders due to a limited understanding of the relationship between health and social care specific to trans people; undervaluing the networks in trans peoples lives; the need to demonstrate culturally competent services and real concerns regarding tackling discrimination and abuse. Despite legislative advancements, there was a sense that activism is central to tackling these issues and trans people are articulating their demands for shaping future provision. The research identifies a number of recommendations for care providers and future areas of research.

INTRODUCTION

Trans is an umbrella term to describe people whose gender identity or expression differs (to varying degrees) from the sex they were assigned at birth (Tobin, 2011). For many trans people, the experience of actualising gender identity can be a journey fraught with complexity, demanding navigation through prejudice, hostility and discrimination to pursue an authentic life. Even when obstacles are overcome, there continue to be flash points in a trans person's life, where disclosure of their former assigned identity can trigger a repetition of these experiences. One such flash point is as trans people age and the need to receive social care increases, particularly personal care. The potential for exposure becomes tangible if gendered parts of the body require attention (i.e. bathing) or if identity paperwork is considered mismatched.

Understanding the potential care needs of trans elders requires an appreciation of the journeys travelled by trans people to realise their identities, alongside a commitment to ensure that services do not explicitly or indirectly repeat discrimination experienced in their younger years. Older trans people face discrimination and prejudice through living in an ageist and cisnormative society, where there is an expectation that everyone is cisgendered or non-trans (Bauer et al., 2009). The term 'cisgender' is a broad reference to individuals whose gender assigned at birth sits in alignment with their self-defined gender identity. Cisgenderism captures the expressions of discrimination and oppression targeted towards trans people and other individuals whose gender identity differs from the gender assigned at birth (Ansara, 2012). Ansara (2012) describes cisgenderism as a form of dominant ideology that feeds negative assumptions about trans individuals as 'disordered' or abnormal. It can also manifest in the pathologising of trans identities and bodies within psychiatry and lead to 'misgendering' in everyday life – (mis)representing a person's gender in a different way from their own self-identity (Ansara, 2015). Combined, transphobic discrimination and cisgenderism create structural inequalities in service delivery that need to be understood by caregivers, health and social care providers, commissioners and regulators if they are to provide dignified and trans-positive care.

Gerontology is generating a wealth of academic literature and research that can assist service design and challenge service providers and policy makers to refresh their thinking about the needs of our generations of elders within our communities. This demands an understanding of all communities, including (and especially) those whose life experiences are journeyed by a minority. Research into lesbian, gay, bisexual and trans (LGBT) experiences acknowledge that trans and bisexual issues are often marginal, if represented at all (Harrison, 2006; de Vries, 2011; Opening Doors London, undated; Hughes, 2006). Researchers have cited the need for more trans specific research to ensure their needs are more fully understood (Lo, 2006; Tobin, 2011; de Vries, 2011), particularly when considering practice in service provision.

'Creating anti-oppressive practice in service provision that successfully remove barriers to the social inclusion of older lesbians, gay men, bisexuals and transgendered (LGBT) citizens has proven thus far tremendously difficult'
(Concannon, 2009, p. 403)

In response to identifying an absence of trans voices being heard on the subject of trans elder care, this qualitative study sought to understand expectations of services, amplify the voices of nine participants and share the priorities they articulated to influence future service design and practice. The aim of this paper is to canvas their concerns, priorities and expectations for future care in later life, if needed, and to articulate a vision of trans-positive care for social care services. Conducted by the first author, this exploratory study generated initial findings in a relatively unexplored field of ageing and gender studies.

RESEARCH METHOD

A convenient sampling method was used as a suitable approach to recruiting participants from a hard-to-reach population in which many individuals may not wish to be visible or identify as 'trans'. Over 200 invitations were circulated through social media channels, using existing trans community networks. Nine trans people, across a range of age spectrums living in the US, Canada and Europe self-selected to participate. Table 1 outlines their demographic information, including self-defined gender and age at time of participation.

[Table 1 about here]

Participants' accounts were generated through semi-structured using Skype as a web-based real-time platform which enabled trans voices to be heard unrestricted and in depth. Interview questions were themed around expectations of aging and perceptions of aged care services. Through a thematic analytic approach responses were coded into broad headings and analysed, enabling comparisons within distinct topics and the identification of recurring themes. Six core themes are reported in this paper.

Ethical approval for the research was provided by Swansea University. The bias of the study was acknowledged, as the participants were drawn from known LGBT networks, are weighted towards those who identify as male/masculine, reflect a Western perspective and have a degree of technological competency.

FINDINGS

Perceptions of aged care services were mixed across the group, with over half having had some level of contact with residential or community care services for older people. A number of participants had experienced these services directly; through supporting family members, their work or the work of close friends or family members and one had, as a child, visited elder facilities with their family as part of their religious ministry. Participants who had not specifically experienced aged care provision had first-hand experience of other forms of care provision, which provided them with an overview of social care services generally. Despite the range of ages, experiences and locations there was a shared perception amongst the majority of the participants that aged care provision was poor for the general population and that this was exacerbated for them by a perceived lack of insight, awareness and readiness to offer a quality service to trans people.

“Terrifying places...it definitely put fear into my psyche as a child...this is where poor people and people who have no family go” (Bravo)

Theme 1: The relationship between health and social care

Universally, participants rated health care needs as a high concern. Specifically, for those who have undergone or are undergoing gender treatment, was the absence of information related to the long-term impact of hormone therapy or surgeries.

“I think that we all take testosterone and we don’t know if it’s going to completely fuck us over...but you’re compelled to do it so...the sense of future is quite narrow...but I don’t think that’s uncommon for people who have grown up not knowing how to exist in the world...I haven’t got a sense of future for my life, so...I haven’t invested in a sense of myself in the future ...” (Hotel)

Avoiding examination or physical intervention is a known response by trans people (Pfund, 2010), exposing them to higher health risks. Participants articulated their concerns in engaging with non-specialist medical professionals:

“Trying to imagine myself having a health concern that is bad enough that I have to go to the emergency room, that’s terrifying to me. I’m so much more willing to sort of take more chances here and there than have to deal with the medical community” (Foxtrot)

“I used to go on the bus, bundled up in bandages and get over to the GP’s nurse because I didn’t want district nurses coming in who might have their own prejudices or faith beliefs that could mean the treatment was different...[I] possibly shouldn’t have been travelling on buses in a highly fevered state” (India)

Avoiding medical treatment could result in increased morbidity rates, for often treatable conditions and so social care providers, who often find themselves in advocacy roles between health services and clients, would benefit from understanding and appreciating these concerns in order to facilitate better service delivery.

Social care tasks often include assistance with toileting, bathing and dressing; with all of these activities comes the potential exposure of gendered parts of the body. Participants stated anxieties about how care staff might respond to people whose bodies do not fit with gendered expectations, particularly if they are too frail or disempowered to challenge any expressed negative views:

“If I need to have any physical care, like being bathed or anything, I don’t want someone freaking out because I have a pussy” (Delta)

Receiving these kinds of intimate care services can be challenging for anyone but for those people whose bodies themselves challenge cisnormative assumptions, there are additional layers of sensitivity that need to be understood:

“What’s between your legs doesn’t necessarily match with what they perceive you to be, you know male or female....if I have care needs when I’m older, to be looked after by staff who are just completely comfortable with my physicality.” (Charlie)

Theme 2: The importance of networks and community

For LGBT people, greater life satisfaction is often predicated on having a positive sense of self, identity and active engagement in community (Orel, 2004) and families of choice and community support networks are often a vital lifeline for older trans people (Fredericksen-Goldsen, 2011; Grossman et al., 2000; Neville and Henrickson, 2010; Blank et al., 2009). The value of kinship with its associated impact on health and wellbeing should not be underestimated.

A number of participants talked at length about the broad social networks they enjoy and actively maintain, stating these nourished and stimulated them politically, socially, academically, philosophically, emotionally and artistically. They discussed the breadth of these networks; encompassing a great diversity of ages, backgrounds and experiences and how these were proactively sustained through real life and online contact. These networks either replaced or expanded family relationships and were a positive alternative to a cisnormative nuclear family that offered, in ageing, great potential for support:

“I have extended queer family...I would hope that we wouldn’t have the isolation of the elderly people that I’m seeing...my extended family is always increasing...so maybe that’s a difference in terms of from an isolated person who doesn’t have that extended family who might only have their partner, and then widowed or less friends as time goes on and there’s the potential we could possibly have more extended family” (India)

Facilitating and enabling trans elders to build and sustain community connections with other trans people may support them to feel included, supported and understood. For those whose needs make maintaining these community connections complex (i.e. through frailty or reduced mobility), it is important that care providers become facilitators to reach out to trans agencies and networks to create connection and belonging. Isolation is a known factor (Williams and Kemper, 2010) in the decline of health and care needs in older people and care providers need to prioritise this work.

Theme 3: The need to provide culturally competent services

With care providers holding on to legacy views about ‘treating everyone the same’ in their care (Barrett and Stephens, 2011; Hughes et al., 2011; Simpson et al., 2015), there is a continued danger that a one-size-fits-all approach to service design is failing to reach out

to older trans people whose life journeys have been so fundamentally different from the wider cisgendered population. Confidence in existing aged care services to meet trans elder's needs is low, with reports indicating a lack of knowledge or commitment to fully understand what offering a culturally competent service could look like (Hughes et al., 2011; Blank et al., 2009). This was reinforced through this research, with participants expressing high degrees of concern about how their care needs will be addressed sensitively in their old age. Culturally competent service delivery requires integration of knowledge about marginalised individuals and communities into specific standards, policies, practices, and attitudes to improve quality and outcomes (Davis, 1997). Within social work and social care, culturally competent practice evolved from a demand to develop ethnically-sensitive practice that was client-centred, drew on cultural resources and enhanced practitioners' understanding of historically marginalised populations (Fisher-Borne et al., 2015). Some authors have argued that this model does not adequately recognise power differentials between the client and the service provider or give sufficient emphasis to the personal responsibility of helping professionals to locate themselves within unequal power relationships (Fisher-Borne et al., 2015). While acknowledging these critiques, this model remains useful for assessing individual practice and service provision in providing trans-positive care.

There was a sense from participants that cultural competence was as much a mind-set as it was the possession of a set of skills, information and associated good practice. Being open minded, non-judgmental and assumption free were some of the ways in which care services could demonstrate and signal their inclusivity.

"Just being really willing to learn...some of my better care providers have just been open to being educated about it, it's not been about them having any prior knowledge but just being open to experiences and then going and educating themselves as a result" (Foxtrot)

There are trans people who are out, who are willing to share their experiences to educate others. There are community agencies that can facilitate this and create cultural experiences that can expand services knowledge and contribute to good practice but these need to be actively sourced:

"I have no problem myself personally with using my body and my life to teach other people but I am very well aware that that's a minority, most people feel really confronted having to do that and so, just because I'm an exhibitionist and I like to talk...what I can do is miniscule, the training I can provide people... people in any kind of caring position need to get some LGBT IQ competence" (Delta)

Aged care services are predominantly delivered person-to-person and have an inherent power dynamic, with clients dependent on the skills, knowledge, tone and style of the staff member to deliver their service in a way that meets their unique expectations. Building the skills, knowledge, confidence, articulacy and empathy of frontline care staff to engage successfully with trans people needs to be prioritised and reinforced through management practice and policy. In particular, using appropriate gender pronouns is fundamental and educating staff to appreciate that some people may prefer less familiar

pronouns (i.e. they, ze, hir) was considered important in educating people about the spectrum of gender identities. There was acknowledgment that this can be difficult for many cisgendered people however creating a safe space for everybody means supporting the right to self-identify.

“Going through customs...because I always have to fill out a landing card...you have to declare male or female...and I never do. I draw a heart in the middle and I put a little X there and...if I have time, I give them a little intersex 101” (Delta)

This is not just about pronouns though; it is about appreciating that the more popular and accepted narrative of ‘boy becomes girl’ or vice versa is not sufficient to describe all trans people’s experiences.

“It’s a whole spectrum and you can’t just get locked into one story and be like ‘ok, I know, you grew up in the wrong body and now you’re in the right gender and you’re finally happy, I get it’ because it’s not that way for everybody” (Golf)

Universally, participants indicated that fundamentally, they wanted to see a removal of cisnormative assumptions, stripping these out of documentation, processes, practice and communication. Removing and challenging any assumptions that explicitly or implicitly exclude people was identified as one of the key expectations of a care service manager as it was acknowledged that this post holder sets the tone, culture and ethos of a service.

Some participants discussed their perceptions that it is often easier for trans men to ‘pass’ in day-to-day life without surgery but that this becomes revealed when requiring any kind of personal care or health care interventions. In this sense, it was felt that there were distinctions to be drawn between those who had pursued surgery and those who had not and the relationship this had to being ‘outed’ in the context of receiving care services. There are specific surgeries and health issues that staff delivering care will need to become comfortable with.

“One of the things you have to do with a vaginoplasty is that you have to dilate the vagina with a medical stent on a regular basis, every 2 weeks indefinitely for the rest of my life...what if I get to the point where I’m physically not as able to do that for myself? How do I talk to them about that? I mean it’s obviously going to be an awkward conversation even if they are trans positive” (Echo)

Trans men who have had phalloplasty surgery may also require specific assistance as they age, to ensure that they remain infection-free and that toileting needs are attended to.

“If you’re receiving personal care and someone is dealing with your toileting needs and your penis doesn’t look like the guy’s penis next door...that’s for me what might be incredibly confronting for staff, they’re gonna need to be super switched on and sensitive” (Alpha)

There are lots of reasons why many trans people opt to have no surgery, or have some surgeries but reject others. Therefore, becoming comfortable with bodies that do not meet gendered expectations is critical to providing a culturally competent service.

It is important to acknowledge that competence in delivering inclusive services to lesbian, gay and bisexual elders does not automatically extend to trans seniors too. While LGBT issues are often considered together, gender and sexuality are not the same. In providing an account of some work with staff in a transitional housing service for clients who are HIV+, one participant spoke of the lack of cultural competency in delivering services to trans people.

“They [the staff] are very aware of gay and lesbian issues and very respectful about that but at times almost willfully ignorant of trans issues... like how to use the right pronouns or respect their name when its different from what their legal name is, stuff like that, really basic stuff “ (Echo)

One participant spoke of how care environments have the opportunity to embrace offering a pronoun appropriate service, perhaps creating a safer space than in wider society.

“In care though, it could almost even be better in a way because if a person has their chart...they’d have their little book...that says all their stuff and it would say ‘preferred pronoun’” (Alpha)

Theme 4: The concerns regarding discrimination and abuse

Discrimination and abuse remain high areas of concern for trans people, who have often experienced a lifetime of prejudice, ignorance and discrimination and have fears about how these could increase alongside the vulnerabilities of ageing. In recounting the traumatic experience of one trans man who was deprived of medical care due to being trans and consequently died, told through the documentary film ‘Southern Comfort’ (Davis, 2001), one participant described the impact:

“He was denied the care because he was a trans man...he ended up bleeding out. This was...in the 90’s, it’s not even that long ago. So, any transsexual who’s ever seen that movie, it’s etched in your mind, that could happen to me” (Golf)

One of the participants discussed a surgical experience, where despite being transferred to a specific hospital in expectation of greater skill and care, he was faced with negative attitudes and almost rejected for treatment due to the inability of the surgeon in this field.

Several participants felt unprotected by current civil rights and equalities legislation. It was felt that agencies interpreted their responsibilities too narrowly with one participant articulating that too many agencies managed their equalities responsibilities through minimum statutory requirements to avoid prosecution rather than through any genuine

commitment to diversity. Participants expressed their concerns about an organisation's ability to manage confidentiality and the disclosure of personal information, demonstrating their keenness to retain some controls over this in order to manage their own safety. While in the UK protections exist under the Gender Recognition Act 2004 for managing confidentiality, not all trans people pursue legal recognition through gender recognition certificates and it would be remiss for organisations to only consider these parameters when dealing with the management of personal information for trans people. The lack of monitoring data in social care organisations creates conditions that exacerbate the invisibility of this group (de Vries, 2011). Acknowledging, understanding and valuing the differences of trans people's life experiences, histories and expectations for the future is critical to designing services that explicitly meet their needs. Many trans people may not wish to be counted and monitored, for a variety of reasons that can include wishing to protect privacy or through concerns that losing anonymity will result in discrimination, rejection or hostility. Clearly, people must therefore have the opportunity to opt out of providing this. However, it is important that organisations find ways to manage data that assure confidentiality and protect individuals from any harm through the creation of appropriate conditions for capturing, recording and monitoring sensitive data.

Theme 5: The expectations of an aged activist generation

As each generation ages, services must adapt to ensure they remain relevant to the needs, expectations and assumptions of older people. Participants involved in activism now have an expectation that this will continue into their old age and that they may benefit as trans elders from the social changes that are taking place in the contemporary world. It is not unreasonable to anticipate that those activists fighting for social and legal equalities will take these experiences into their retirement years and continue to challenge discrimination, exclusion and invisibility where this is experienced. Providers will need to be prepared for generations of trans activists who will be less inclined to tolerate cisgenderism and have the experience, confidence, abilities and networks to challenge exclusion through social and legal action.

Some participants felt that much of their activism work now was about seeking to influence a future world that would be a place to thrive, as opposed to survive. Their work on pursuing greater social justice now was as much about tackling current challenges as it was about preparing for a future as aged trans people.

"I've been focusing through my activist work and...I think the cumulative effect of all the work I do will hopefully mean that in the future there will be a space for me to exist in the world." (Echo)

Theme 6: The aspirations of future care provision

The issue of whether there was a need to develop trans or LGBT specific elder care services came up repeatedly and different views were expressed. One participant felt strongly that mixed, integrated services would be his preference with another indicating

that while this would be his option in an ideal world, current reality meant he felt he would receive care more tailored to his needs through a trans or LGBT specific service.

"I just saw recently in the news...transitional housing space for...trans women, where it was just a house where a whole bunch of trans women who were elderly got to live and they had a care worker...and I remember seeing that and thinking that is so perfect." (Echo)

Two participants would prefer to receive trans specific care services while the fifth felt that as he had more in common with radical queer heterosexuals than assimilationist LGBT people, his preference would be one that offered a service aligned to values, as opposed to identity.

"I would choose a queer orientated thing over anything else because I think that this signals to me a deeper commitment to the individual...I would choose a GLBT, queer, whatever, over something else" (Foxtrot)

Remarkably, when describing the ideal elderly residential care environment, the participants who expressed a view articulated a vision that shared many characteristics. They described a facility that was situated within one location, where there would be a variety of accommodation offers to satisfy individual needs. These included independent apartments, with visiting staff available as required and accommodation designed to suit those with higher care needs. The preference was for the care to flex around the needs of the individual but it was recognised that in some cases, where care needs are highest (e.g. nursing care) it might not be practical or possible to remain in the same apartment but they would prefer to stay within the overall facility. Any changes to immediate physical environment would be mitigated by familiarity with the overall geographic location, the grounds and gardens, the neighbours and wider community, the staff team, the amenities, and the overall culture and management of the place. One participant articulated how this model would allay any concerns about having to re-tell his story with each move:

"I think it's probably preferable because all the staff would already know and I wouldn't have to come out over and over again. Or have it be discovered and then having to deal with the repercussions of that. I think that's ideal for me." (Foxtrot)

A few participants expressed the view that there could be a role for independent advocacy in aged care services, with people employed specifically to engage with trans people to establish how positive their experiences are in these services. They could act as intermediaries between the needs of the clients and the providers of the service to find solutions to any issues, difficulties or challenges that are being experienced.

While some providers are responding by developing LGBT specific models of aged care (GLEH, 2013; see also Ross, 2016 in this special issue), there is a balance to be made between providing safe spaces for trans elders to age and creating ghettos that let mainstream providers 'off the hook' in delivering culturally competent services. The challenge for care providers is to consider investing in models that cater specifically for

the needs of trans people but to ensure that this does not mean they disinvest in improving the ability of mainstream services to meet the needs of trans elders. Creating care products that enable agencies to become the 'provider of choice' for trans people may well mean a radical overhaul of their culture, policies, processes, skills and approaches are required, enabling access into new markets of opportunity.

CONCLUSION AND RECOMMENDATIONS

It is within the gift of care providers to tackle the many issues and concerns for older trans people identified in this research. As highlighted here, while the intention may well be that providers are pursuing services that are delivered equitably, this is unlikely to be achieved without adapting to individual experience. It is therefore critical that services move beyond the position of 'we treat everyone the same' to valuing diversity and the unique experiences of all individuals. This potential for social care services to unintentionally or deliberately reinforce exclusion is significant, potentially resulting in many trans elders being prevented from enjoying their concluding years free of the discrimination that has likely characterised much of their lives. For providers and their staff, understanding the impact on an individual of feeling unsafe in public, living in fear of reduced life expectancy and experiencing sexual and physical violence in the home is of great significance (Krehely and Adams, 2010; Kenagy and Bostwick, 2005; Kenagy, 2005; Nemoto et al., 2005). Understanding the resistance of a trans person to having constantly changing carers as a result of these experiences could equip providers with rationale for adapting protocols.

Agencies can educate staff to become more trans aware through a variety of techniques, tools, narratives and methods that enable them to reflect on their own assumptions, challenge their perceptions safely and create an environment where discussion of trans issues (and gender identity more broadly) is natural and encouraged. Systemic discrimination can be challenged by reviewing policies, procedures, protocols and processes to remove conventions and assumptions of cisnormativity. This will facilitate a culture of working in an open, inclusive and assumption-free way.

With higher rates of living alone and being single amongst trans people (Whittle et al, 2008), agencies need to understand the role and significance of alternative families and networks. These networks are often not afforded the same legal protections as biological families or legally married/partnered people. This needs to be considered by care providers who can build policy in embracing a broader concept of family and provide information that supports this for their staff and their clients. Welcoming the extended networks and communities of trans people with the same enthusiasm as biological families are welcomed into care planning will signal to trans people deep insight into their life experiences and be highly validating. In addition, facilitating the maintenance and development of wider community networks through pro-active outreach as well as online will likely enable trans elders to thrive.

This study has been exploratory in design and has set out to bring a number of issues and concerns for trans older people from a range of national contexts to the attention of

social care providers and commissioners and to therefore set an agenda for developing trans-positive care. However the issues raised here are by no means exhaustive and there are numerous directions for future research in this field. A number of participants discussed faith and culture, both in terms of wanting theirs to be respected as well as concerns about some care staff from different faiths and cultures being less tolerant. One participant also raised concerns about how their sexual choices and activity would be viewed in aged care services. These are fertile ground for future research that could help reinforce trans-positive care. In addition, a number of participants discussing death, suicide and dying; end-of-life care is another area where greater research could support more effective social and palliative care of trans people.

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Table 1

Participant information including assigned pseudonym, location, age and self-defined gender

Pseudonym assigned	National location	Age at time of participation	Self-defined gender
Alpha	United States (US)	55	Trans-man
Bravo	US	36	Gender queer
Charlie	United Kingdom (UK)	57	Trans-male
Delta	Sweden	55	Intersex; Trans-masculine spectrum
Echo	Canada	26	Woman; Transsexual; Trans-woman
Foxtrot	US	33	FtM (Female to Male)
Golf	US	42	Transsexual man; FtM
Hotel	UK	37	Trans-masculine
India	UK	55	Trans-man